2nd National Stakeholder' Meeting Report

April 10 - 11, 2001

Atlanta, Georgia

Centers for Disease Control and Prevention

prepared by:

Capital Consulting Corporation (CCC)

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I. EXECUTIVE SUMMARY

Since 1995, the Centers for Disease Control and Prevention (CDC) has been working with key partners and stakeholders to develop, implement, and evaluate the National Electronic Disease Surveillance System (NEDSS). A goal of NEDSS is ongoing, automatic capture and analysis of data of public health significance from public and private health entities.

On April 10-11, 2001, CDC held the 2nd National NEDSS Stakeholders' Meeting in Atlanta, Georgia. The purpose of this meeting was to inform stakeholders and partners of the progress made in the planning and implementing NEDSS at all levels, as well as to receive input for future NEDSS activities. CDC also hoped to increase awareness of current and future NEDSS activities. In total, over 400 representatives from state, local, and Federal agencies and private organizations attended the two-day conference.

The two-day meeting consisted of plenary, workgroup, and panel sessions. The opening plenary session provided updates on NEDSS activities. Working group sessions focused on Integrated Data Repository (IDR) and data modeling; electronic messaging; data analysis, visualization and reporting; security; and creation of a directory of public health personnel who would have access to the system. Meeting participants also attended panel sessions focused on inter-governmental and public-private relationships; public health information infrastructure; policy issues (including data sharing, access and confidentiality); relationships between NEDSS and other programs; and the Health Insurance Portability and Accountability Act (HIPAA).

Following the workgroup and panel sessions, each group presented its concerns, outcomes, recommendations, and discussions. The following summarizes the meeting outcomes:

- ***Base System –*** The NEDSS Base System is a platform upon which surveillance systems, processes and data can be integrated in a secure environment. The Base System is a modular system that is a platform to support state notifiable disease surveillance and analysis activities. The Base System will support state and local surveillance activities, provide a seamless view and management of cross program data, support the storage and maintenance of data in an integrated database at the state level, and provide access to specific commercial off-the-shelf (COTS) products to support data analysis and visualization activities. States will not be required to use the Base System in their individual surveillance systems. It is meant to be available to states choose this option rather than building their own system from scratch.

- ***Security –*** NEDSS is working to clarify specific implementation of the NEDSS security standards and how these will work with state security approaches. To facilitate this process, it was recommended that each state appoint a security liaison who will act as the point-of-contact for security issues. Security liaisons would also be expected to participate in future communications, meetings, and teleconferences concerning security issues.

- ***Communication –*** Maintaining communication was a major point of discussion in almost every breakout group. Pilot states that shared their experiences at the meeting stressed the importance of states maintaining communication with stakeholders and key partners. Methods they employed included e-mail newsletters, meetings to update and obtain feedback, focus groups, teleconferences, and telephone hotlines to obtain input from stakeholders**.** An important mechanism for contact among states, CDC, and other stakeholders is CDC's WebBoard conference, on which anyone can post concerns, and share ideas, information, reports, and software.

- ***Collaboration –*** To ensure that NEDSS is successful, collaboration among Federal, state, local, and private participants is essential. It is important that states accommodate the viewpoints and requirements of their stakeholders when designing their surveillance systems. The states should view their stakeholders as customers who must be satisfied if they are to "buy in" to the NEDSS concept.

- ***Standards –*** The effort to create standards for NEDSS is still ongoing. Data, security, and messaging standards need to be finalized. The Public Health Conceptual Data Model (PHCDM) will facilitate the effort to create public health data standards.

A more comprehensive summary of the 2nd National Stakeholders' Meeting is provided in the following sections of this report. Appendices at the end of this report provide additional information on the meeting, including the meeting agenda, presentations from the meeting, meeting attendees, the program committee, and a glossary of terms.

II. PURPOSE OF MEETING

On April 10-11, 2001, CDC held the 2nd National NEDSS Stakeholder Meeting in Atlanta, Georgia. The purpose of this meeting was to inform stakeholders and partners of the progress made in the planning and implementation of NEDSS at all levels, as well as to receive input for future NEDSS activities. CDC also hoped to increase awareness of current and future NEDSS activities. The conference was designed to facilitate discussion and foster collaboration and consensus among the local, state, and Federal agencies as well as private organizations. The objectives of this meeting were to:

- Increase understanding of NEDSS
- Demonstrate and explain the concept of the NEDSS Base System
- Provide opportunities for state and local representatives to compare notes and share experiences
- Strategize about NEDSS linkages with the Health Alert Network (HAN) and categorical programs
- Address some of the policy issues raised by NEDSS and relationships between local/state/Federal agencies.

III. MEETING DESIGN AND METHOD

In collaboration with representatives from stakeholder organizations, CDC planned and developed the April 10-11 meeting objectives and agenda. Meeting participants included invited representatives from state and local health departments, CDC, public health professional associations, Federal agencies, and other health-related organizations. In total, over 400 representatives from state, local, and Federal agencies and other organizations attended.

The conference began with a plenary session designed to introduce and provide an update on NEDSS development. Topics presented during this session included: the framework for public health information technology, partnerships with local health departments for the purpose of surveillance, and an update on NEDSS extramural activities. The highlight of the opening plenary session included an introduction to the NEDSS Base System. John Loonsk and Mike Rigden provided a functional overview, a technical overview, and a description of the process and data modeling characteristics of the Base System.

Following the plenary session, meeting participants attended a NEDSS workgroup session of their choice. Five workgroup sessions were designed to update meeting attendees on NEDSS element development in that workgroup's concentration, and/or obtain input from attendees on what is needed and next steps. Concurrent with the workgroup sessions were sessions to introduce NEDSS to new participants in NEDSS implementation activities. The five workgroup sessions were:

- Session B1: Integrated Data Repository and Data Modeling Workgroup
- Session B2: Electronic Messaging Workgroup
- Session B3: Data Analysis, Visualization, and Reporting Workgroup
- Session B4: Security Workgroup
- Session B5: Directory of Public Health Personnel Workgroup

The following morning, meeting participants attended two of six possible panel sessions. Each panel was guided by a CDC moderator and a state or local representative.

The six panels were:

- Panel A – Realizing NEDSS: The Importance of Inter-governmental and Public-Private Collaboration
- Panel B – Building the Public Health Information Infrastructure
- Panel C – Opportunities for Public Health through Vital Statistics and NEDSS
- Panel D–Policy Issues Around NEDSS: Data Sharing, Access, and Confidentiality
- Panel E – NEDSS Relationship with Other Programs
- Panel F – Implications of the Health Insurance Portability and Accountability Act (HIPAA) for NEDSS

Participants could also elect to attend educational sessions on Data Modeling and eXtensible Markup Language (XML) at this time.
The remainder of the meeting focused on presentations of the workgroup sessions and panel sessions. Dr. Broome closed the meeting by thanking program planners and participants for their hard work and commitment to NEDSS, and outlined next steps to generate support for full implementation.

The following sections summarize the opening plenary, workgroup sessions and panel session reports, recommendations, and discussion.

IV. OPENING PLENARY

A. Keynote Address: A Framework for Public Health Information Technology: Extending the NEDSS Concept

David Fleming, Deputy Director for Science and Public Health, CDC

NEDSS represents a logical outgrowth of efforts to improve collaboration between traditional public health and the health care delivery system. Dr. Fleming provided a description of the NEDSS concept and summarized implementation activities since March 2000.

A key goal of NEDSS is the ongoing, automatic capture and analysis of data that are already available electronically. It represents an integration of public health and health care data systems designed around relevant data sources, not diseases. Since March 2000, a NEDSS data standards framework has been developed and the architecture elements for a state NEDSS system have been defined. Funds have been provided to state and selected local jurisdictions for assessment and planning ($3.6 million, 42 awards), element development ($3.997 million, 12 awards), and more comprehensive programs in two charter sites ($2.285 million). In Fiscal Year (FY) 2001, awards totaling $21.680 million will be made for these purposes, plus awards to several key coordinating organizations. Meetings of participating organizations have been held and coordinating committees established.

NEDSS is designed to address limitations of current surveillance systems. Limitations include the multiplicity of categorical systems, incomplete and untimely data, unacceptable burden on health care system respondents, the overwhelming volume of data to be managed by health departments, and lack of state-of-the-art information technology.

NEDSS is based on the following principles: utilization of industry system standards; reliance on "off-the-shelf" software; Internet-based secure transmission of data; a common "look and feel" of systems; common reporting requirements; and no requirement to use specific software. NEDSS system architecture is allowing several CDC surveillance systems to integrate, including the National Electronic Telecommunications System for Surveillance (NETSS), the HIV/AIDS Reporting System (HARS) and systems for tuberculosis (TB) and other infectious diseases. A Base System utilizing NEDSS standards is being developed by Computer Sciences Corporation (CSC), an experienced web software engineering company, in consultation with CDC and state partners. It will be available to states in the coming months and will undergo integration testing in one to three states in FY 2001. The system is designed to be used at the state level as a platform for specific modules that states can add to in the future to meet their needs.

Discussion Points

A question and answer period followed the presentation.

- ***Availability of the Base System –*** *Should states wait until the CDC Base System is developed, or proceed in developing their own?* In conducting assessment and planning, states will consider the best approach for their circumstances; CDC will make information on Base System available to assist in decision making.
- ***Evaluation of NEDSS –*** *How should we measure the success or failure of NEDSS?* First, we need to measure how well we implement the processes of NEDSS. In the long run we need to evaluate how well NEDSS helps us improve the delivery of public health services.
- ***Consistency of NEDSS implementation within CDC and by other Federal agencies –*** *Will other CDC and other Federal programs adopt the NEDSS approach?* We are in an early stage of implementation and CDC will move quickly to adapt current surveillance systems to the NEDSS approach. CDC and its state and local partners need to work with respective counterparts in health care financing and delivery programs, among others, to demonstrate how the use of NEDSS principles, and especially the use of national standards, can help them do their jobs better.
- ***Adequacy of funding levels and funding arrangements –*** *Will other CDC grant resources be available to help implement NEDSS?* Will CDC fund localities directly? CDC grants will be available for NEDSS development, but resources for NEDSS also need to come from all other possible sources at the state, local, and Federal levels. The key is to describe how the system is consistent with the states' individual missions and legislative requirements. With regard to direct CDC funding of local agencies, direct funding will be provided to selected localities, but CDC feels that states are in a better position to work with localities in developing and supporting their systems. CDC is providing support through the Health Alert Network (HAN), which is directed to increase local health department IT capacity.
- ***Legal Issues –*** *There are legal concerns around sharing records and confidential information. Have these issues been addressed?* NEDSS is committed to being compatible with Health Insurance Portability and Accountability Act (HIPAA) standards. However, some of these issues will need to be resolved at the state and local level.
- ***Local Roles –*** *How do local health departments fit into the NEDSS picture?* Currently, six metro areas receive grants for NEDSS development. Interested partners need to look at different models that will incorporate local health agencies and meet their needs. HAN, which is committed to helping local grantees, is also participating in NEDSS development. Many details remain to work out on a case-by-case basis, but we would like to focus on the role of local health agencies at this meeting.

B. The Delivery System as Surveillance Partner—Hope or Hype?

Richard Platt, Professor of Ambulatory Care and Prevention, Harvard Medical School, Harvard Vanguard Medical Associates, and Harvard Pilgrim Health Care

Modern public health surveillance challenges include bioterrorism, anti-microbial resistance, emerging infections, and influenza. The health care delivery system can play a vital role in meeting these challenges, particularly in generating needed data, but public health must carefully think out the strategies they use to get the cooperation of the delivery sector. Those who deliver health care are very busy. Reporting public health information is low on the list of challenges and opportunities they face. They often forget what is reportable by law and have different ideas about what is of public health significance. Faced with burdensome demands for providing information to others, their major concerns are providing information that helps them deliver quality health care and get paid for their services. They also have concerns about privacy and liability. However, managed health care plans have much in common with public health activities in several important respects, and we can build on these commonalities. They serve defined populations, acknowledge prevention as an important part of health care delivery, have limited resources, collect and use data, and can intervene to improve the health of the populations they serve.

Dr. Platt described preliminary data from a series of pilot programs that he and others had carried out in Eastern Massachusetts. These programs evaluated data from managed care organizations and compared it to data reported to public health agencies, demonstrating that pharmacy records and claims forms can supplement reporting of diseases like tuberculosis (TB) to health departments. Pharmacy reports of prescriptions for two or more commonly used drugs for TB were a particularly sensitive method of identifying unreported cases. For detection of respiratory diseases, chest x-ray records were another source for finding unreported cases, although physicians often manage Lower Respiratory Infections (LRI) without benefit of chest x-ray. Preliminary work has been done to compare ambulatory visit codes by census tract for certain LRI with reports of influenza, TB, and other respiratory diseases. LRI reports matched expected national influenza time trends, but correlation with TB cases was not apparent. Further analysis is planned focusing on disease rates, subpopulations, obtaining real-time reports, automated detection of events, and syndromes other than LRI.

Discussion Points

A discussion period followed Dr. Platt' s presentation.

- ***Accuracy of Data*** – Concern was expressed about miscoding of information in the various originating systems. This was acknowledged as a problem and should be evaluated on a case-by-case basis. Some data could be used as a sentinel surveillance system, requiring follow-up investigation and validation. It was noted that miscoding already plagues the public health reporting system.
- ***Privacy and Confidentiality –*** Concern was expressed that using data from these systems for public health purposes might be in conflict with the privacy requirements of the Health Insurance Portability and Accountability Act (HIPAA). These problems were addressed in the Massachusetts project on the rationale of carrying out research and study. An exemption permitting access to identifiable health information for public health purposes is included in HIPAA.

- ***Public Access to Surveillance Findings –*** *Can demographic and geographic data about the occurrence of events might routinely be shared with the public?* It was suggested that this can be done, but carefully so that individuals are not identified.
- ***Collaboration with the Massachusetts Department of Health –*** The importance of close collaboration between public health agencies and health care providers in exploring uses of health care data was emphasized. Cooperation in Massachusetts was early and ongoing.

C. Update on NEDSS Extramural Activities

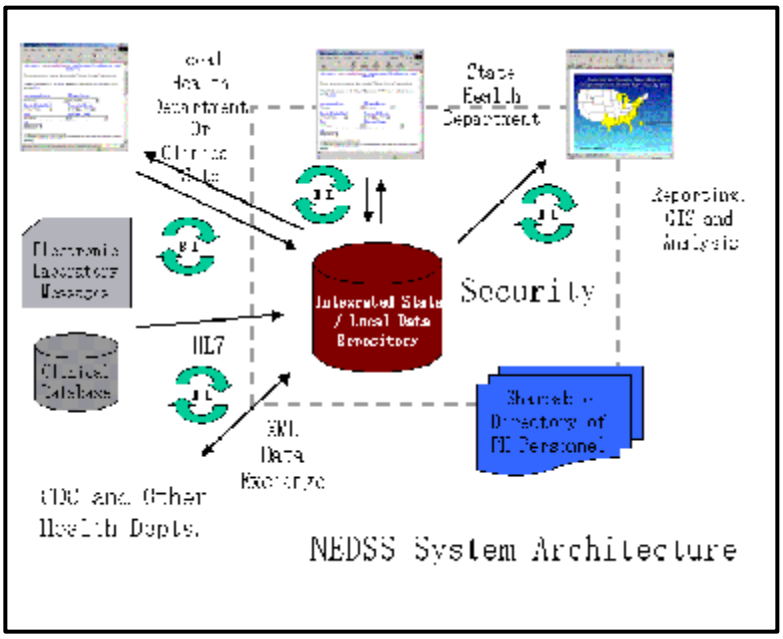
Bob Pinner, National Center for Infectious Diseases, CDC

Last year, NEDSS funded 12 states to develop NEDSS data elements, 2 states as charter sites, and 36 sites to complete assessment and planning activities. There were more requests for funding than expected and a large number of jurisdictions are currently involved in NEDSS development or ready to begin development. Extramural funding totals for this year are approximately $21.6 million. The goal is to fund as many sites as possible and add new element development sites and charter sites. However, the average award will decrease from about $450,000 to $333,000 per site. Work on the NEDSS Base System, which will provide software that implements NEDSS standards and supports integration, is also well under way. States will have the option to propose use of the Base System in the FY 2001 Grant Proposal. Questions about the awards should be directed to Dr. Pinner (Rpinner@cdc.gov).

D. The Base System: Implementation of NEDSS Standards and an Option for Use

John Loonsk, Associate Director for Informatics, CDC
Mike Rigden, Computer Sciences Corporation (CSC)

Dr. Loonsk opened the discussion of the Base System by providing an overview of future goals for the system. The first step is to move from "Conceptual Standards" to "Concrete Standards" in the development of the Base System. There is a strong drive toward using national standards wherever possible, but ensuring that they meet public health needs as well. It is also important to realize that the standards will change as the information technology industry grows and matures.

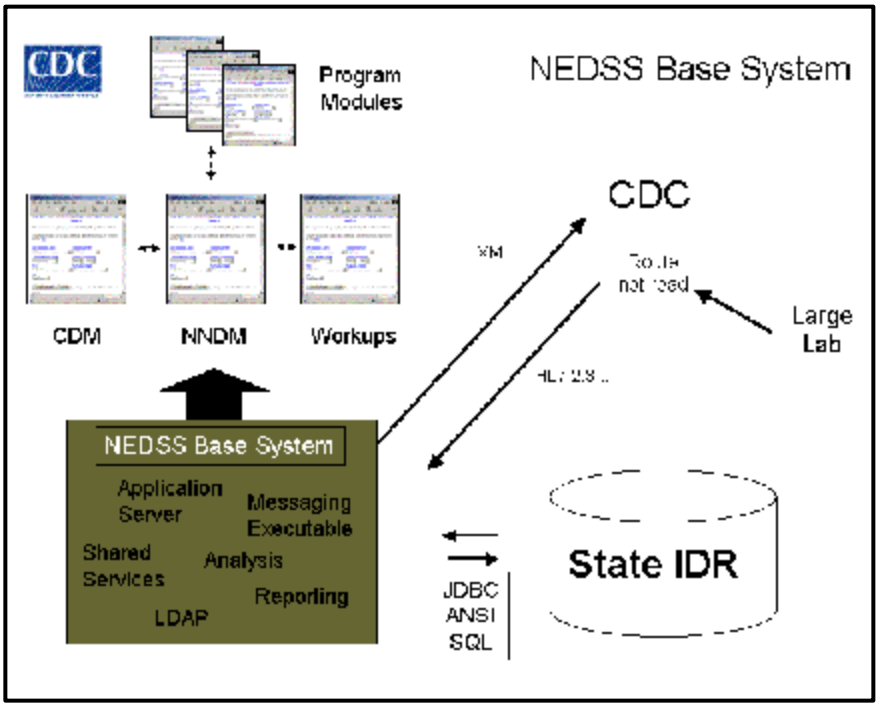


2Figure 1. NEDSS System Architecture

Figure 1 shows a schematic of the NEDSS system architecture. Aspects of the architecture include security, a messaging component, integration broker technology, a core integrated data repository, a shareable directory of public health personnel, and transportable business logic. The system should be modular to the degree possible; the goal is to set up a scalable platform for sharing data. The architecture elements will use industry and *de facto* standards, but will try to minimize the dependency on any one commercial-off-the-shelf (COTS) software. The intent is to build the NEDSS system around elements that are functionally and technically defined, have *de facto* standards, facilitate the use of commercial software, minimize dependency on a particular software, and facilitate exit strategies for using new software later.

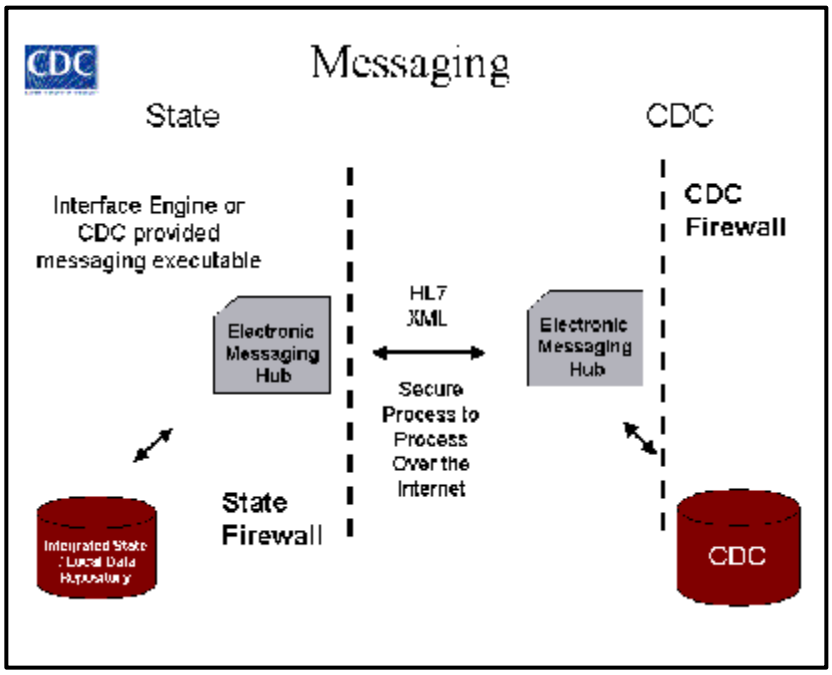
3Figure 2. NEDSS-to-State communication

The Base System software is broken down into the Core Demographic Module (CDM), Nationally Notifiable Disease Module (NNDM), core data and systems functions to support program area modules (PAMs), and a limited electronic lab reporting system. The commercial software products involved are a SilverStream application server, Eclipsys E-link messaging tool, VeriSign digital certificates, Statistical Analysis Software (SAS) for analysis, and potentially others as the Base System develops. Dr. Loonsk expects that all applications of the Base System will fit on a



4Figure 3. Secure Messaging

single application server machine. The system will interface with the state's Integrated Data Repository (IDR) using current Oracle structure query language (SQL) Server



Database Management System (DBMS) software though the Java Database Connectivity (JDBC) and SQL standards. Data will be exchanged with the CDC through the application server vis HL7 Version 3.0-based. In addition, CDC will collect and disseminate the data through Health Level 7 (HL7) 2.3 format from large clinical labs to states in a "route not read" fashion. See Figure 2 for a graphical depiction of this process.

In order to be functional, the system needs to be a flow of information among the web modules. The state can receive information for the Base System's CDM and PAMs using eXtensible Markup Language (XML) messaging and eXtensible Stylesheet Language (XSL) templates. Transfer of data between the states and the CDC will use strong security standards. The goal is to have the Base System integrate well with existing firewalls without opening holes. The Base System also plans to use the state's existing authentication message, whether it is token- or certificate-based for Internet access or a username/password combination for Intranet access. Information will be transported across the Internet using secure pipelines and field level encryption and VeriSign digital certificates ensuring an audit trail. Messaging hubs located at the state and the CDC will use Health Level 7 (HL7)-compliant XML to transfer data bi-directionally. Figure 3 shows these hubs in reference to the state and CDC firewalls. The CDC hub will be in front of the main firewall, but behind another for security purposes. If a state lacks the necessary security infrastructure to use the Internet, the Base System can function using a state Intranet.

Mr. Mike Rigden continued the presentation by describing the application functionality of the Base System. The Base System is a set of enabling technologies needed to solve business value issues. The process used for refining NEDSS functionality consists of a discovery phase, a preliminary design phase, and an application functionality phase. The application functionality will include program

management, person-based surveillance, aggregate surveillance, person intervention, population identification, and intervention. The first release of the NEDSS Base System will focus on some but not all of these areas.

Mr. Rigden's discussion focused on person surveillance. The key process model concepts for person surveillance include:

- Multiple types of Entities (Persons, Non-Person living subjects, Organizations, Groups, Materials, and Places
- Each type of entity can include multiple types of roles and close-entity role relationships can be related to specific activities that they perform.
- Multiple types of Activities: Observations (lab results, clinical results, field reports, etc.), Investigation Work-Ups, Cases, Notifications, Patient Encounters, Interventions, and Referrals.

Current surveillance systems provide the entry and reporting of observations (events) but do not provide support for work-flow management and collaboration. The Base System will allow for the entering of events observations, creation and management of work-ups, bulk data entry of paper form-based Case Reports, Notifications, Analysis, Visualization, Reporting, investigator work-flow queues, automatic capture and routing of electronic lab and clinical results.

The presenters briefly discussed some of the other functional issues of the NEDSS Base System. Additional details can be found in Mr. Rigden's PowerPoint presentation in Appendix C.

In conclusion, the presenters remarked that the Base System should be viewed as a package containing architecture systems and services, messaging standards, integrated repository standards, a set of software code from CDC, packaging of support for Integrated Data Repositories (IDRs), registry management, and direct assistance via grants for base system integration support. In June 2001, there will be integration testing of the base system in one to three states followed by a beta release sometime after October 2001. A series of program modules that will sit on top of Base System will be available at that time. The process for development of the base system requires state involvement in developing core modules. Therefore, state feedback is critical and necessary to the development of the system. States can provided feedback on the draft requirements documentation posted on the NEDSS WebBoard

Discussion Points

Following the presentation, there was a question and answer period.

- ***IT Issues –*** *States may have problems interacting with their IT people while developing NEDSS. There will be a need to integrate state and Federal resources. At the state level, we will need to help with resources and make intelligent requests for help from IT departments. What are they and what do we say to get help?* States will need to commit IT resources and actively collaborate with IT personnel to ensure successful implementation of NEDSS. A software solution is being developed, but use of the Base System will still require state IT capacity.

- ***Communication between States –*** *Currently, CDC will route data from commercial labs and will not read identifiers associated with the data. Will state-to-state communications work that way?* The ultimate goal is for the NEDSS Base System to support the creation, routing, and receiving of electronic messages from any system that supports the standards that the Base System supports. As a first step, the Base System will support the routing of electronic lab results from national labs through the CDC router and to the states.
- ***Unix and the Base System –*** *Will existing Unix systems be able to interface with the Base System?* The Base System is independent of operating system. The standards supported by the Base System are supported on all of the major operating systems, including: Unix, Linux, Windows, and MVS. Likewise, the system will support an IDR residing on any Relational Database Management System (RDBMS) that supports the SQL standards. CDC provided software components will operate out of the box on SQL/Server and Oracle DBMS.

- ***Messaging*** *– Can states and other agencies use CDC's message software, engine, and security to support our applications?* Yes, the license agreement permits the use of these components of the base system. With respect to messaging, the states will need to use to build the Base System, or obtain a development license if they wait to create state specific translators.
- ***Compatibility with other Federal Agencies*** *– As the NEDSS Base System is developed, will there be consideration for it being compatible with and able to access state Medicaid databases?* NEDSS is meant to use generic standards for data and architecture. Therefore, it could link to Medicaid databases if the standards are compatible. This could also limit a state's reporting burden. It is critical at the state level to consider what the standards-based NEDSS approach could facilitate for other data utilization, including Medicaid. The Health Insurance Portability and Accountability Act (HIPAA) data security standards currently being developed by the Health Care Financing Administration (HCFA) will be incorporated in NEDSS as applicable.
- ***Base System Codes –*** *Will Base System codes be made available to states that are not using the Base System?* The codes will be available to anyone, but if the codes are changed by the state, they may no longer work with the Base System. As technology advances, the Base System codes will be versioned; it is the state's responsibility to keep track of the various versions of the Base System codes. The goal is to share as much information with the states as possible.

V. WORKGROUP SESSIONS

A. Session A: NEDSS to Date

Claire Broome, Senior Advisor for Integrated Health Information Systems, CDC

NEDSS is a set of standards for information systems that will be inter-operable for bioterrorism and epidemics, making rapid responses possible. Preparedness for facilitation detection of bioterrorism or epidemics requires that all partners be part of a surveillance system. The current system in place is inadequate, incomplete, fragmented, and slow. The development of national standards for surveillance systems is currently possible due to progress in technology, standards for health electronic data interchange (outlined in the Health Insurance Portability and Accountability Act (HIPAA)) and funding for NEDSS.

In FY 2000, the National Electronic Disease Surveillance System (NEDSS) was created with $20 million made available for this purpose. Ten million dollars went to 14 states for NEDSS compatible development and to 33 states and 3 metropolitan areas for assessment of current information systems and how they could be modified to meet NEDSS specifications and standards.

At the inaugural NEDSS National Stakeholders' Meeting held in March 2000, long-term objectives for NEDSS were stated:

- Ongoing, automatic capture and analysis of data.
- Use of data already available in electronic form
- Designed around data sources rather than diseases
- Integration of data from both public health and health care systems.

The steps laid out at that meeting were to establish standards for both data and system architecture that makes NEDSS able to integrate data across jurisdictions. It is necessary to take a collaborative approach across categorical programs and to develop sophisticated security standards to ensure confidentiality.

The Public Health Conceptual Data Model (PHCDM) was developed as the basis for data standards to enhance data exchange capabilities with health care providers and public health partners. It also helps to represent public health data needs to national standards organizations.

There are eight elements in the NEDSS architecture. These elements are defined by industry standards and the standards of existing commercial products. They accommodate the use of commercial software as elements and will allow NEDSS to take advantage of new commercial software development. NEDSS is a web-based system which allows the system to be easily upgraded on the server without upgrading each individual computer. The security system is designed to allow data entry over the Internet, while providing the technical capacity to restrict access to authorized users.

At the request of state health departments, CDC has a contract with Computer Sciences Corporation (CSC), an experienced web software development company, to develop a Base System. The Base System is a NEDSS-compatible system that will be a platform for use at state health departments. It can support a range of program area modules.

Discussion Points
Following Dr. Broome's presentation, the session turned to a group discussion of NEDSS.

- ***Updating Current Reporting Systems –*** The NEDSS reporting system includes sexually transmitted diseases, infectious disease, tuberculosis, HIV, vaccine preventable disease, bioterrorism, etc. A core activity of NEDSS is surveillance, including analysis and reporting of data.

- ***Marketing –*** Several participants suggested that CDC "market" NEDSS with brochures designed to explain the system and its capabilities.
- ***Availability of Software –*** The software that has been developed to date is owned by the government, and therefore is available and free to anyone. CDC would like to see commercial companies develop future software, but the market may be too small to attract the private sector.
- ***Contact Person –*** Information about NEDSS is posted on CDC's website. The Office of Integrated Health Information Systems coordinates these efforts at CDC.
- ***Grant Timelines –*** Concern was voiced that the timelines for NEDSS grant applications are unreasonably short. CDC is trying to make this process simpler by creating a single category for everyone's applications this FY.
- ***Facilitating State Information Sharing –*** CDC is encouraging partners to share experiences and information on the NEDSS WebBoard. State sites can post what they find works or does not work on the WebBoard to facilitate other states' development.
- ***Health Level 7 (HL7)*** – HL7 is currently relevant to NEDSS in two ways: 1) as a messaging format, and 2) as developer of a national standards data model for clinical information,
- ***Expanded Staffing Needs –*** There was concern that this system will require more staff to set up and maintain. Although more state IT capacity is needed, this is related to the central role of information in public health, and the opportunities new IT provides. NEDSS can help states make this investment effectively.

B. Session B1: Integrated Data Repository and Data Modeling Workgroup

Greg Fetter, Minnesota Department of Health
Greg Pierce, National Center for HIV, STD, and TB Prevention, CDC

IDX Corporation Site Visits

Mr. Abdul Malik-Shakir, from IDX Corporation, reported on the site visits by IDX Corporation to the 12 states that were awarded Federal funds to develop integrated data repositories (IDRs). The purpose of the site visits was to meet with primary contacts for the awards, provide states with an opportunity to ask questions, promote the bi-directional understanding of goals, engage in dialogue, identify action items, and establish a communication link.

Common goals were found among the sites. These included electronic reporting of disease, electronic connection of laboratories, and electronic public health records. Some sites had additional long-term goals, including the goal of integration with other state databases. Sites were working on centralized reporting or centralized repository. A few sites were moving on to consolidating lab results and disease data across program areas and a few had progressed to the level of attempting to integrate disease and case data. However, sites were managing the scope of their task by not trying to take on all aspects of IDR development at once.

Common technologies are also guiding states. Oracle, Sybase, SQL, and DB2 were identified as candidates for systems implementation technologies. Proposed data modeling tools included Erwin, Rose, Visio, and ER studio. UNIX, Multiple Virtual Storage (MVS), and Windows NT were widely considered for operating systems. Development tools under consideration include J Builders, SilverStream, Oracle Designer, and Web Sphere. At the design level, there is no incompatible technology tool; however, the Base System will consist of "example" software and designs based on J2EE. Some tools, such as Visual Basic and C++ will be incompatible with the base system because they do not natively run in a J2EE environment. However, if states want to build their own environments, there will not be any incompatible software tool.

The sites did not all take the same development approach. Essentially, three basic approaches were being used: 1) some sites were developing a single integrated database to replacing current program databases; 2) other sites were building a single database with an interface to current programs; and 3) still other sites were developing a "virtual repository" or collection of databases with common identifiers and semantic repositories. Sites were also in various phases of their element development. Most sites remain in the planning and assessment phase, while a few have moved on to confirmation and design. So far, no states have begun beta testing or converted legacy data.

Many opportunities for collaboration were observed during the site visits. These included the following: publishing the first normal form of the Public Health Conceptual Data Model (PHCDM); publishing design guidelines and/or a common IDR logical model; working with common definitions and data models; sharing reusable business logic for person-case matching and Geographical Information System (GIS); and sharing findings from the reverse engineering of CDC-supplied software data structures and constraints.

In addition to opportunities, challenges exist for states involved in element development. These include multiple funding sources, addressing local jurisdictional and private interests, converting old data, data security, and end user training.Mr. Shakir cautioned that current plans to fully develop integrated data repositories by October may be overly ambitious. He also noted that limited information technology resources within health departments, large number of stakeholders, limited general resources, and legal constraints may limit the speed of development of IDRs. IDX recommendations to public health departments are to start small and build on successes, collaborate within departments, re-use efforts by other departments, seek to involve local health departments and the private sector, measure success, under commit, over communicate, and celebrate interim achievements.

The next steps IDX identified for itself are to prepare project scope and functional specifications, construct logical data models, conduct assessment of state-developed data models, finalize the site visit report, and publish interim updates. The IDX site visit report completion date was set as April 21, 2001 and the report was subsequently slated to be posted to the WebBoard.

State-by-State Report on Current Status of IDR Development State representatives from Charter states provided a short status report on NEDSS activity in their state.

- ***Ohio:*** About one-third of the total project is built. The object design is done and testing will begin in one month. A disease reporting event-based system is being built. Web-based access is being expanded in phases to hospitals, laboratories, and health departments. Health Level 7 (HL7) message imports and exports will be used. Subjects covered by the system include demographic, disease, user security, disease programs on a logical level (including surveillance), tuberculosis (TB), and sexually transmitted diseases (STDs). Functionally, the system will provide event review. There will be manual links on person and events. There will be no case management or autolinking of cases. The system will have the capability to search and edit events. Maintenance will take place at locations and jurisdictions will be sharing use. SilverStream is being used as the portal feature for security. Windows 2000, Oracle 816, and J Developer/J2E are being used.

- ***Minnesota:*** The project is still in the assessment and planning phases. The primary work is focusing on modeling surveillance. External stakeholders' meetings are taking place. There will be a surviving legacy database containing HIV data because of cultural challenges. A collaboration has been undertaken with the immunization registry. Oracle 8x is being used.
- ***Wisconsin:*** The project has a clear vision but is still in the planning and assessment phase. There is a great deal of interest in mapping and a virtual repository. There is also interest in capturing vital records. The ideal situation is to have the communicable disease database talking to labs, before rolling out others. The biggest challenge for Wisconsin is getting the word out to programs within the state that communicate with CDC.
- ***New York:*** The state currently has a number of different program areas using electronic reporting. Workgroups have been organized to implement NEDSS. New York will be moving its database design into Erwin. The platform they are using is UNIX. Web Logic, Oracle, Sybase, and Java are also being used. The goal is to develop a virtual database.
- ***New Mexico:*** Development is in the assessment and planning phase. An advisory committee has been formed. The approach is to start small by first working with databases they have control over and then moving into other databases. The project is using Windows 2000, Whistler, Java, and software provided to them by Los Alamos Labs.

- ***Utah:*** The project is in the assessment and planning phase. Process modeling is serving as a starting point. The project is taking the form of developing a single, real, integrated database.

- ***Colorado:*** The state plans to pilot NEDSS using Laboratory Information Management Systems (LIMS) software between laboratories and epidemiologists. Conceptual and logical data models have been completed. The current goal is to ensure that the disease reporting application is working from the same model as the CDC base system. Colorado is using only Microsoft products.

- ***Pennsylvania:*** The project is working with communicable disease and vaccine preventable illnesses using Microsoft and Oracle products. They are thankful for help from New York's and Ohio's project designs. Windows 2000 and Erwin are also being used. The project received $750,000 for web development from the state. The state itself is also the location of a Microsoft public key infrastructure (PKI) development project. They are working to develop their data security.

- ***California:*** The state is starting in the assessment phase. A repository is being developed for HL7 message data from microbial disease labs. Certain reportable disease data are being collected and the project will expand to collect other data. Local health departments and private labs will need to be involved and their collaboration is being sought.

- ***Nebraska:*** A paperless public health lab ordering system is currently in place. No modeling has yet taken place and there is an effort to retrofit previous work.

- ***Kentucky:*** The state currently has a centralized patient repository and is striving toward a single system model. The effort started as an immunization data registry and now has case management capabilities. The initial goal was to eliminate other databases. However, old systems will need to be integrated and data modeling will have to be undertaken.

No representative was available from Oregon or Washington.

Evolution of the Public Health Conceptual Data Model (PHCDM)

Mr. Shakir presented a series of slides on the evolution of the PHCDM. The presentation focused on the changes between versions 1.0 and 1.1 of that model.

The model continues to stay close to the HL7 reference information model, which has also recently been updated, but the PHCDM is not in lock step with the HL7 model. The original model consists of four subject areas: parties, materials, locations, and health-related activities. Referencing graphical representations of the models, the group discussed some of the changes to the HL7 model as well as the PHDCM. The new version of HL7 introduces the concept of "entity" (party and material together), changed participation to roles, borrows the locator term and calls it "location," identifies the physical characteristic of location, calls organizations "entity groups," creates a new class called an "entity role," and has several additional changes from the earlier version. Among the changes made to the PHCDM were the addition of a class code and a health-related activity, deletion of the class of "specimen," the renaming of the class medication to substance administration, and the addition of a secondary association between entity role and entity.

The PHCDM will continue to change. Multiple events will influence the model, such as data types specifications, message specifications, vocabulary specifications, alignment with national standards, and IDRs. In the future, a process for changes to the model will be coordinated by CDC staff, including harmonization with HL7.

Discussion

Under the direction of the moderator, the workgroup moved toward discussing the current status of the PHCDM and the process for reducing through normal forms of the model distributed in the workgroup bearing the title "NNDM-LDM0321D-10—Display 1/Main Subject Area." The moderators indicated that design of the model had not been completed and that the workgroup's input was needed. The model distributed in the workgroup does not contain all the changes referenced in the earlier discussion relating the evolution of both the HL7 model and the PHCDM. Due to the complexity of the model and limited time available, the moderators noted that the group was probably too large to be a working group and scheduled a lunch meeting for the following day to discuss the particulars of the model with those interested.

As a final comment, the moderators noted that an updated version of the model will be released within two months. The model will be placed on the WebBoard and the designers are eager for feedback.

Meeting Outcomes

The Integrated Data Repository Workgroup discussed several topics during its meeting.

- IDX Corporation has visited all of the technical assistance sites and identifies several common themes. Preliminary recommendations and the IDX report on their findings will be posted to the WebBoard.
- Ten states reported on their IDR development progress. Five states are in the assessment and planning stages. The other states are at various levels of modeling, prototype testing or in production.

- IDX Corporation also presented on the evolution of PHCDM. It was clear that there were no drastic changes from version 1.0 to version 1.1. IDX is working to maintain harmony with the HL7 format in the development of PHCDM.
- CSC presented its progress in the development of the Logical Data Model for NNDM. CSC invited comments and challenges on the draft model they presented at the session. An interim model will be published on the WebBoard in three weeks with the "final" model posted on the WebBoard in five to seven weeks.
- The IDR Workgroup also held an additional meeting on Wednesday, April 11 in which the reverse engineering of the Tuberculosis Information Management System (TIMS) was discussed. Also addressed was the chance to take advantage of "opportunities" identified during the site visits, e.g., CSC and Ohio developing common core code sets.

C. Session B2: Electronic Messaging

Greg Smith, Washington State Department of Health
Tim Doyle, Epidemiology Program Office, CDC
Sam Groseclose, Epidemiology Program Office, CDC

The workgroup began with a discussion of progress made on objectives or issues established during the January 2001 NEDSS meeting. While a great deal of progress had been made toward accomplishing those objectives, more needs to be done. It was evident that communication between the various disciplines involved (e.g., IT personnel, laboratorians, programs, and managers) needs to be maintained.

Objective 1: Catalog of Ongoing Electronic Reporting and Messaging Projects

- CDC has compiled a list of electronic messaging projects in the states on the WebBoard. Participants felt that this list needs to be periodically updated.

- Laboratory personnel indicated a desire to know what progress is being made as they are not involved in the daily electronic reporting and messaging activities.

- Samples of the projects could also be posted on the WebBoard, which would provide a snap shot idea of what is going on. This should spur interaction among states and increase responses.

  It was concluded at the end of the discussion of Objective 1 that a catalog is needed. States need a way to exchange information with their data trading partners. CDC could start this process by routinely posting changes or updates on the WebBoard.

Objective 2: Share Information on Product Evaluations and License Agreements

- The Base System will include a license for a messaging tool to interchange messages with multi-jurisdiction labs and CDC.
- The evaluation of products and the criteria used for this evaluation are fairly informal; useful information may require a pilot implementation. People that have information post it on the WebBoard. CDC needs to be careful that when something is posted (either good or bad), that it is not construed as an

endorsement. CDC has a much broader implementation plan than the states, so their "evaluations" may not be appropriate for the "small package" states. CDC can talk to the states individually about the criteria they used to evaluate eLink, eGate, eBiz. The states should also look at their functional requirements and do a feasibility study. The goal is to obtain different perspectives.

- Thirty-six states are in the process of assessment planning/evaluation and it would be good to know their results. It was suggested that CDC could get a CSTE-type organization to post the results or progress to date to reduce the issue of endorsement. Assessments that have been performed will be used by the states to determine where they are in the process; CDC also can use the information to determine where the states are.

Objective 3: Input on Standard Formats/Messages for Electronic Reporting
It is necessary that messaging work with Integrated Data Repositories (IDRs).

- ***eXtensible Markup Language (XML)*** – The role of XML in messaging has not been clarified yet. Some participants feel that a "white paper" needs to be developed. XML is good for encoding messages and could serve as a format for storing documents. However, a clearer scope of what it should do is needed. XML is already working in HL7 messaging, enabling the encoding into versions 2.3 and 3.0.
- ***Systemized Nomenclature of Medicine (SNOMED)*** – A description of how to obtain SNOMED authorization is on the web. There are three tables that have been authorized for use: 1) living organisms, 2) modifiers, and 3) disease (including all that are reportable). Initially, SNOMED was thought to be more robust but, in actuality, it is not. Any suggestions for improvement would be greatly appreciated. In a comparison of NEDSS event codes to the SNOMED disease listings, 75% of NEDSS events codes were found. Some of the items not found are unique to public health and SNOMED would be willing to add these to their disease listing. ICD codes could probably not be fixed to relate to SNOMED. Additionally, the Health Care Financing Administration (HCFA) felt that insurance companies would likely use terms like "suspect" inappropriately. There was some brief discussion about mapping that is done by the states, the use of two sets of codes, and the need to continue to improve the SNOMED version 3.0. Probably the best thing to do with coding is to move to Federal licensing of SNOMED. If SNOMED were used by the states to evaluate their own reporting issues, it would likely be legal under the licensing agreement. CDC sent the authorization forms for SNOMED to the states; they were signed and returned to CDC. This process not only created a record of the authorization but also identified a single point of contact. Once approved, the state will submit a list of not more than 100 laboratories that will be allowed to participate. The process for renewal of the license is being worked on now. CDC needs to know who is using SNOMED. CDC will also work directly with the national laboratories such as Lab Corps and Quest Diagnostics.

NEDSS Electronic Messaging – Messaging Methodology: Requirements for Messaging

Following the discussion of the workgroups objective, Mead Walker from IDX Corporation spoke to the workgroup on NEDSS electronic messaging.
NEDSS requirement of standard messaging and communication in public health involves state and local health departments, health care providers, reference laboratories, and CDC – at a minimum. In order to have efficient communication, standards must be used and must consider of the uniqueness of public health and its relationship with the wider medical community.

Electronic communication is an area of great activity. The Health Insurance Portability and Accountability Act (HIPAA) largely mandates the use of Accredited Standards Committee X12 (ASC.X12) yet HL7 is universally used by hospitals and many other health care providers. Using existing standards is vital for effective disease surveillance in that it eases the burden of implementation for reporting laboratories and reduces research and development costs.

Most of the states and many laboratories have experience in NEDSS and the HL7 Unsolicited Observation Report (ORU) to transmit data to health departments and to CDC. HL7 has spent eight years and substantial organizational resources defining a process for message development. The information model plays a central role in taking advantage of the Reference Model Repository. The NEDSS functional requirements are posted on the WebBoard. The tight relationship between the Public Health Conceptual Data Model (PHCDM) and HL7 makes mapping from one to the other much easier. To reconcile conflicts in definition or code, either suggest changes or use another domain.

The Unified Modeling Language (UML) has defined two diagrams that show communication between two objects to support the requirements (use cases) of a system. The Collaboration Diagram captures the parties (objects) within the system and shows the information exchanges needed. The Sequence Diagram shows each party as a vertical bar rather than a box. This allows for focus on the dependencies between messages and on their temporal sequence.
Currently, the flow of information is among state health departments, laboratories, and CDC. All laboratories are pretty much the same in their relationship with state health departments. The state also has the responsibility to identify potential duplicate reports. In addition, an "implementation guide" needs to be developed. Anything beyond the Base System is a "work in progress." For example, hospital reporting needs to be better defined, including specialized areas such as laboratory and medical records. The role of HMOs, additional payers, pharmacies, and the Medicaid Program needs to be clarified.

Wrap-Up
The workgroup wrapped up its meeting with a call for better communication among all the people involved in the development of NEDSS.

Meeting Outcomes
This workgroup discussed a number of issues and developed action plans for each.

- Three objectives that were developed during the January meeting were revisted during this workgroup session.

    a. Develop a Catalog of Messaging Projects Underway -- CDC is to compile a list of CDC level messaging projects and post them to the WebBoard. States will then add their own messaging projects to the catalog.
    b. Share Information on Product Evaluation and Licensing Agreements – The workgroup will use information provided to develop recommendations for CDC on broad use of COTS products.
    c. Input on Standard Formats and Messagtes – It was determined that collaboration between the IDR workgroup and the electronic messaging workgroup is necessary to facilitate data management issues.

- SNOMED Update – States need to provide CDC with a prioritized list of local labs that will use SNOMED licenses and coordinate the ditribution of the licenses.
- NEDSS Base System Message Development – All information on message development activities will be posted to the WebBoard. Meeting attendees are encourages to comments on the model and the type of messages.
- Notifiable Disease Notification Message Content – A matrix of data elements and coding will be posted on n the WebBoard. Meeting attendees were invited to comment on both the data elements and the codesets used to represent data elements.

D. Session B3: Data Analysis, Visualization and Reporting

Rebecca Johnson, Minnesota Department of Health
Tonya Martin, National Center for HIV, STD and TB Prevention, CDC

The session opened with an overview of the Data Analysis, Visualization and Reporting (AVR) System workgroup. The goal of this system is to make surveillance data (canned reports, user-defined and customer reports, and datasets) available via the Web and other methods. The use of real-time surveillance data and architecture not only permits sharing, but also addresses security and data user concerns. The moderators encouraged participation in the AVR conference on the CDC WebBoard, where CDC and Minnesota have posted criteria for selecting and testing AVR products. The Minnesota criteria includes: ease of use, degree of documentation, analytic capabilities, and the type of assistance and training available.

SAS Institute Update

Ms. Hope Toupin from the SAS Institute (SAS) reviewed the current status of the licencing agreement between the Department of Health and Human Services (DHHS) and SAS. Language originally in the agreement allowed DHHS grantees to have access to SAS software for analyzing and presenting NEDSS data. Unfortunately, this language was removed, but efforts are underway to reinstate the original language in the agreement. Some restrictions may be added to limit access to only certain software applications. Meanwhile, CDC and SAS are investigating interim provisions for NEDSS grantees. Ms. Toupin also said that SAS would be providing more information to the states on available SAS products and functional applications.

Demonstrations of AVR Applications

- ***SAS Institute Enterprise Guide –*** This application allows users to tap the full power of the SAS system with an easy-to-use, task-based, familiar Microsoft graphical user interface. The Guide connects the user's PC to any Version 8 SAS System Server and allows that user to access any data types supported by the SAS system, utilize the execution power of that machine to run any SAS processes, and return professional reports and graphics to the user's PC. Bryan Sheff, from the SAS Institute, used the Enterprise Guide and data from the Indian Health Service to demonstrate the point and click interface using simple dialogs and wizards. Although a windows-based product, data may be pulled from other operating systems and from multiple sources into a single table. There is also a built-in quality check to assure that no data are lost during transmission. For user defined reports, the Enterprise Guide programs outputs from the whole database not just predefined data – not just predefied data elements.

- ***CDC's Epidemiology Program Office (EPO) –*** This demonstration used data from the National Notifiable Disease Surveillance System (NNDSS) located on an EPO application server. Using a real-time connection from the PC in the conference room to the EPO server, both ad hoc and structured outputs were demonstrated – with data appearing in less than 30 seconds. The demonstration was a "proof of concept" and showed how an authorized user would have direct access to a database and could download data for analytic purposes. Discussion focused on the policy issues involved in establishing such a system within a state, but no clearance currently exists for wider use.

- ***New York State Department of Health*** – In 1997, the Communicable Disease Unit began implementing an Web based electronic reporting system at the local health unit level (LHU). Prior to this time, the system was entirely paper-based. The objectives of the system are to enhance rapid reporting, integrate local and state communicable disease information, and increase public health responsiveness to infectious disease outbreaks. The system was pilot tested in selected counties for six months and then made available to all counties.

  Each user signs in and is allowed to perform only specified functions. For example, STD staff are allowed entry only to the STD areas of the system. There are built in quality checks, and supplemental data screens are available for special collections. LHUs are able to download copies of the state reporting form to print and distribute to providers, helping to ensure adoption of the latest revisions. The system is established on a SAS background and users are able to develop a variety of outputs. The state also has a public web site with a full report menu.

  Currently 44 of 57 counties are actively using the system. There is currently no laboratory participation, but a pilot test is underway. The primary cost relates to the initial technical assistance and training required to establish the system. Maintenance cost are minimal and are borne by the State Department of Health. LHUs must run dual systems until they achieve a consistent error rate of less than 3%.

  The primary benefits of the system have been:
  - Decreased reporting lag (time elapsed from the report to the LHU to the State Department of Health has been reduced from 11 days to 5 days among those LHUs using the system)
  - Presence of a uniform database
  - Ease of case report submission and updates
  - LHU query capability
  - Readily accessible state reports
  - Increased confidentiality
  - Greater flexibility
  - Establishment of a common interface for multiple applications

Implementing Geographical Information System (GIS)

Several workshop members asked for advice in implementing GIS. There was general discussion about successes experienced by Connecticut and Minnesota with environmental health issues. The Web site of the Agency for Toxic Substances and Disease Registry (ATSDR) was also cited as a good source for information.

Wrap-Up

The session concluded with recommendations for next steps to:
- Broaden representation
- Share evaluation criteria for tools
- Exchange information and experiences in testing and/or implementing tools
- Share templates, routines, etc.
- Use the NEDSS WebBoard and conference call for communication.

Meeting Outcomes

- During a brief overview of the AVR Workgroup, it was suggested that evaluation criteria for evaluating products for analysis developed by states and/or CDC develop should be post to the WebBoard.
- Even though language that included DHHS grantees in the SAS licensing agreement was removed, there is an effort to reinstate it. In the meantime, SAS and CDC are investigating interim provisions for grantees.
- There were several demonstrations of products during this workgroup session.

    a. A brief presentation on the SAS Enterprise Guide and SAS/Internet application for the Indian Health Service project.

    b. Representatives from CDC conducted a proof-of -concept using the SAS/Internet product showing that it can be c=used to develop a web-based application. By accessing the National Notifiable Disease Surveillance System (NNDSS) during the presentation and conducting structure/ad hoc queries , they were able to demonstrate what can be accomplished in a short development time period..

    c. A representative from New York State demonstrated a communicable disease reporting wen-based system that was developed a few years ago.

- A few next steps were also identified.

    a. To continue to share with grantees and others through the NEDSS WebBoard what is happening concerning the development of AVR routines. templates, etc.

    b. For CDC to continue working with SAS to develop a broad template that would meed the reporting needs of states and locals.

    c. To address issues around security, confidentiality and appropriate data use.

E. Session B4: Security

Ivan Gotham, New York State Department of Health
Robb Chapman, Epidemiology Program Office, CDC

The workgroup began with a quick review of the discussion from the January NEDSS meeting. The moderator addressed the need for greater participation by the states and the lack of progress to date. He proposed that each state assign a security liaison who can be a point-of-contact for NEDSS security issues.

The workgroup's charge was to define the processes, controls and (standardized) technology required to ensure sufficient levels of "trust" between organizations so that they would consent to engage in electronic interchange of confidential information over the Internet.

Public Key Infrastructure (PKI)

Several states expressed serious issues about cost and time involved in using PKI as a standard for NEDSS. States currently vary in levels of implementation and use different forms of PKI. Agreement is needed on how to handle Certifying Authorities (CA), Registering Authorities (RA), and Certificate Revocation Lists (CRL). The workgroup also noted the need for:

- Individual authentication
- Process-to-Process Authentication and Messaging
- Strong Encryption.

Trust Agreements

Ivan Gotham from New York State Department of Health presented overviews of needed components of a Trust Agreement and General Controls. It is important legally to have trust agreements in place between all institutions that will be sharing information. These contracts needs to be a guarantee of integrity and authentication of users. Since every institution has differing requirements, it is not feasible for all states to use the same agreement. Agreements need to take into consideration acceptable and sufficient controls. Some controls to consider are: human resources, audit trails, and controls over access and application development.

Wrap-Up

The group agreed to continue discussions on the NEDSS WebBoard. The moderator reiterated the need for a NEDSS Security Liaison in each state to ensure participation and to have a standard means of communication between CDC and the state. Mr. Rob Chapman (rchapman@cdc.gov) will act as the main contact at CDC and proposed a deadline of May 1, 2001 for every NEDSS grant site to name a liaison. Future communication will be primarily through e-mail and the WebBoard, with a scheduled monthly phone conference. The liaison's first task is to report on the state's security policies, processes and requirements by sending an e-mail message to Mr. Chapman or posting a profile to the WebBoard. The security liaison will also be responsible for providing examples of security agreements and participating in a model "trust agreement" that will act as a boilerplate for agreements between states.

Meeting Outcomes

- No agreement was reached at this meeting concerning PKI individual authentication. There were numerous questions regarding practicality and trust. This issue will be discussed further at future workgroup meetings.

Process-to-process authentication and messaging seems to be the only proctical solution.

- A general model of a trust agreement is needed. Contents of the agreement might include non-discolsure/confidentiality, appropriate use, gurantee of integrity of authetication.identification, organizational responsiblity for actions of individuals/employees, auditable internal controls, and compatibility with HIPAA. Acceptable and needed controls for these agreements also need to be developed.

- The next step for this workgroup is to identify a security liaison for every NEDSS development site by May 1, 2001. The security liaison needs to possess a background in IT and local health programs and be familiar with local polities. Activities for this position will include participating in the Security workgroup through the WebBoard and on monthly phone conferences. The tasks assigned to the security liaison are to research and report on state security policies, processes, and requirements; to develop a profile of each stated describing the types of security task involving website authentication; provide examples of security agreements; and participate in the development of a model "trust agreement."

F. Session B5: Directory of Public Health Personnel

Joseph Reid, Associate Director for Science, Information Resources Management Office, CDC
Robert Hall, California Department of Health Services

The primary objective of this workgroup was to discuss the process to develop a Lightweight Directory Access Protocol (LDAP)-compliant directory for and of public health workers and organizations. The directory would be maintained locally but shared more widely as appropriate, e.g., to identify the current contact person(s) for emergency response. The workgroup began with a comprehensive and detailed review of technical, operational and policy issues related to implementation of a LDAP-compliant directory. These included directory schemas and namespaces, entry object classes, replication and referral strategies, security architecture, and levels of decision-making (Federal, state, local and participant levels). Consensus was reached on best practices for many of these issues. The workgroup will continue to work together through the WebBoard and teleconferences. Sub-task workgroups were established to concentrate on specific issues. These sub-task workgroups are:

- Person Entry Object Class Design
- Organization Role Entry Object Class Design
- Replication/Referral Strategy Design
- Directory Security Design
- PHDIR Vision and Marketing

Meeting Outcomes

- This workgroup is working under a number of assumptions that were discussed during the workgroup session.
- Five sub-task workgroups were establish with work recommendations.

a. *Person Entry Object Class Design* – develop a recommended format for directory namespaces (DN's) in the Reference Schema. There needs to be

a DN for state-based organizations and non-state-based organizations. This sub-task workgroup should also recommend object classes for phPerson, phOrganization, and phRole.

b. *Organization/RoleEntry Object Class Design* – make maximal use of other's people work, e.g., phPerson should be modeled on inetOrgPerson, etc.
c. *Replication/Referral Strategy Design* – CDC could establish a clearinghouse for LDAP Data Interchange Format (LDIF)/Signed Document Markup Language (SDML) fields used to update the Public Health Directory Service (PHDIR) Reference Server so that they may be used to support mirroring on other servers. The LDIF-based approach should be replace with an XML-based approach.
d. *Directory Security Design* – Standards for the positioning of referrals in the directory tree of the Reference Server should be established.
e. *PHDIR Vision and Marketing* – No recommendations were made during this session.

- The LDAP workgroup also established a number of next steps.

a. Establish a committed membership.
b. Make effective use of the WebBoard for communications.
c. Establish sub-task groups.
d. Draft formal work plans.
e. Begin drafting standards and sop's using the internet engineering taskforce request for comment model.

VI. PANEL SESSIONS

A. Panel A: Realizing NEDSS: The Importance of Inter-governmental and Public-Private Partnerships

Moderators: Art Davidson, Denver Public Health Department
Blake Caldwell, Public Health Practice Program Office, CDC

The implementation of NEDSS depends on successful collaboration across government agencies and between private and public agencies. During this session, participants discussed issues, presented examples and suggested approaches and directions for realizing productive collaborations. Malcolm Adcock from the Cincinnati Health Department, Richard Danila from the Minnesota Department of Health and Patricia Maloney from Quest Diagnostics presented their experiences with collaboration and electronic reporting and surveillance systems and the lessons learned from this process.

Malcolm Adcock

The Ohio Disease Reporting System (ODRS), a project funded under NEDSS is in Phase 1 of development, Electronic Reporting of Communicable Disease. Ohio has 88 counties with a total of 144 local health agencies. Under the ODRS each local agency must communicate with each other as well as with the Ohio Department of Health. The type of data needed from this system is population incidence/rates and case information; however, the state and local health departments are at odds on how to use this information. At the state level, surveillance is the main concern while at the local level, the focus is on case management and disease intervention. Traditionally surveillance occurs in real-time, but at the local level there is a need for real-time intervention. Collaboration will be necessary to resolve these issues, but the prospects for collaboration are strengthened by the presence of numerous public health networks. Not only is there a strong working relationship between local health departments, the state health department and CDC, but also the Health Alert Network (HAN) has allowed for a communication channel to be opened between all levels of public health.

In designing the ODRS system, a needs-assessment was performed before and after the project was funded. A chatroom was opened on the web for input into the design. From this collaborative design process, a list of local requirements for ODRS was developed.

The development of ODRS taught many lessons:

- Collaboration between stakeholders is very important.
- Stakeholder involvement and feed-back throughout development is critical.
- Business rules of system operation are as important as those encoded into system.

a. Private providers are not motivated by the needs of a public health mandate. Legal requirements do not necessarily ensure acceptance.

- Systems must add value and enhance collaboration in the reporting process.

- Technical functionality does not guarantee success. A reporting system should not add more work to the process.

- The system must assist in the control of infectious disease.

Richard Danila

Equal partnerships are critical to the success of NEDSS. In Minnesota, there is a strong tradition of successful public-private partnerships among the medical community, local health departments, other state agencies and various schools at the University of Minnesota. Early in the NEDSS development process, Minnesota staff identified stakeholders and formed a NEDSS advisory task force. They also interviewed stakeholders to discovered what was most important in the system's development. Throughout the process, stakeholders have been involved through newsletters, e-mails, websites, local meetings, faxes and a telephone hotline.

Numerous challenges have arisen in the development process:

- *Keeping existing partnerships strong* – Approaches to this challenge have been to increase electronic communications, keep partners updated on NEDSS activity and provide information to partners on future activities so that partner systems can migrate to those standards.
- *Helping existing partners with needed changes in staffing roles and functions* – Approaches to this challenge include discussing training plans with representatives of the Association for Professionals in Infection Control and Epidemiology (APIC) and the Minnesota Interlaboratory Microbiology Association (MIMA), clearly articulating the benefits and involving partners in setting priorities.
- *Helping existing partners with needed changes in the organization* – Approaches to this challenge have been to help obtain administrative buy-in, facilitate internal discussions at their organizations and identify their internal stakeholders.
- *Adding new partnerships* – Approaches to this challenge have been to identify the key organization contacts and meet fact-to-face with other organizations to demonstrate the benefits NEDSS can bring.

Two important lessons learned by Minnesota were: the need for individual and organizational relationships in order to ensure long-time success of NEDSS; and the importance of maintaining strong, constant ongoing communication to keep all partners satisfied.

Following Mr. Danila's presentation, there were a few questions from the audience.

- ***Role of Doctors and Infection Control Practicioners (ICPs) –*** *What is the future use of NEDSS for doctors and ICPs?* Within a year, there will be online access to NEDSS. At that point, more labs will be online and more online reporting tools will be available.
- ***New Staff –*** *How are job functions being adjusted to accommodate the additional roles and functions that NEDSS requires?* In Minnesota, three new staff were hired with NEDSS funding. It has been difficult to find IT personnel willing to work for the state government and also have a background in health.
- ***Collaboration with Labs –*** *Have private labs been receptive to collaboration concerning NEDSS?* Minnesota laboratories have had good experiences working with our surveillance in the past so they "buy into" the NEDSS concept. They have been incorporated in small steps.

Patricia Maloney

The lack of a standard format for transmitting public health data electronically impedes successful collaboration. To address this issue, the goal became adoption of a single, standardized Health Level 7 (HL7) format through a collaborative effort with local health departments and health centers. Quest Diagnostics approached this challenge by creating an Internal Steering committee, whose members included CDC and state representatives. This Steering Committee meets monthly to discuss progress and issues. With this Steering Committee, Quest has made two significant accomplishments: 1) the creation of an atmosphere conducive to open dialogue, and 2) the implementation of a single HL7 format.

Despite this progress, many key issues remain unresolved. Many state and local health departments lack equipment, expertise and funds to implement NEDSS. The private sector does not have the ability to obtain required information because physicians do not voluntarily provide it. The reporting criteria required at different levels is not consistent. There is also variability in data elements and standards.

The lessons learned by Quest Diagnostics to date are:

- Collaboration between stakeholders is essential.
- A single standard format is required.
- Standard reporting criteria and flexibility of required information will facilitate better compliance.
- The system must add value and enhance collaboration in reporting processes.

Discussion Points

Following the presentations made by the panelists, there were a few questions from the audience.

- ***Collaboration with Physicians –*** *How can physician reporting be improved?* It was suggested that CDC work with the American Medical Association (AMA) to train physicians to do better reporting to improve reporting. Others felt that we should view physicians as customers. As physicians see and experience the added value that NEDSS will provide them, they will be more willing to participate. In more rural areas, where physicians are reluctant to report in order to protect their patients, local health departments should be encouraged to do face-to-face surveillance to help build trust in the system.
- ***Collaboration with Laboratories –*** *Concern was voiced that some labs, especially small local labs, are not interested in NEDSS. Should incentives be created for labs to participate?* One option is to encourage trade association to meet with lab personnel and to better understand the issues. For example, if it a lab has trouble getting required patient information from physicians, perhaps a solution such as " closing the loop" would help. If physicians are pressured by local health departments for not reporting all required information, they might be more willing to provide all the required information up front.

Meeting Outcomes

This panel focused on three themes in inter-governmental and public-private relationships. These themes were collaboration, planning a communication.

- *Collaboration*

  < Diverse organizational viewpoints are inherent to any collaborative effort. This diversity must be understood by all parties involved through frequent communication and inclusion during the planning and implementation phases.
  < In order to enhance buy-ins in collaborations, providers physicians, local health departments, etc.) should be treated as customers by working to make reporting information useful to them and encouraging personal interactions.

- *Planning*

  a. During the planning phase, identify all stakeholders early and include them in the process.
  b. A critical review of the work flow should also be conducted during the planning phase.
  c. It is also important to place NEDSS at a higher level than within one state program.

- *Communication*

  a. In terms of communication within NEDSS, establish standards that facilitate getting work done.
  b. Access to and functionality of a reporting system may need to be rather broad.
  c. Ongoing communication must be maintained with partners. It is particularly important to establish mechanisms for feedback.

B. Panel B: Building Public Health Information Infrastructure

Moderators: Denise Hase, Northeast Colorado Health Department Ed Baker, Public Health Practice Program Office, CDC

This session focused on how NEDSS and the Health Alert Network (HAN) are related in their jurisdictional roles and responsibilities, working relationships and interactions/communications. Dr. Ed Baker from CDC's Public Health Practice Program Office, Tim Broadbent from the Massachusetts Department of Public Health and Robert O'Doherty from the Colorado Department of Public Health and Environment presented their experiences with the development of HAN and NEDSS infrastructure.

Ed Baker – Building the Public Health Information Infrastructure: The Health Alert Network and the National Electronic Disease Surveillance System

Dr. Baker provided an overview of implementation of the Health Alert Network (HAN). HAN is designed to assist States in developing communications networks and information resources, building distance learning capacity, and developing standards for response to health emergencies. Among states receiving HAN funding, 55% of local jurisdictions have developed high-speed Internet links, 82% have satellite downlinks, and 56% have alert broadcast capacity. This work will establish important communications standards and capacity in support of NEDSS implementation.

Dr. Baker also discussed the Frist-Kennedy Development legislation that was signed into law on November 13, 2000. The legislative intent of this bill is to build capacity to assure preparedness of local, state and Federal health agencies, provide uniform assessment methods and authorize grants and technical assistance to assess and enhance capacity and system performance. Frist-Kennedy will help build the infrastructure necessary for new communication systems, including HAN and NEDSS.

Tim Broadbent

Mr. Broadbent discussed implementation of HAN and NEDSS in Massachusetts. HAN links public health professionals and others in the state through a single web portal. HAN officials focused on planning and functional design before actually developing the system using NEDSS and other national standards, including those related to clinical and claims information mandated by the Health Insurance Portability and Accountability Act. The Massachusetts system is web-based and modular in design, and thus can serve as a portal to various applications including surveillance. Mr. Broadbent described the security measures and user controls that have been adopted, and the approach employed to enlist cooperation of the many participants in the system, including help in sharing costs. During Phase One of implementation, HAN is focused on providing health alerts, news, training, a document library, an updateable directory, and discussion groups.

Robert O'Doherty – Building an Infrastructure

From experience in developing NEDSS infrastructure in Colorado, Mr. O'Doherty recommended selecting development tools early in the process and sticking with that platform. Colorado chose Microsoft because Microsoft developers were more abundant in the market and cheaper than other types of programmers. The next step was to install a "base" (not to be confused with the NEDSS Base System). This base provided a core system for Colorado around build modules, and included the hardware, software and development tools. Implementation began with a few early adopters committed to designing the system and demonstrating its value to others. These included the Colorado Electronic Disease Reporting System and the Integrated Registration and Information System. Mr. O'Doherty suggested that states should seek financial help from a wide variety of sources, including the Immunization Program, Year 2000 initiatives, Medicaid, the Preventive Health and Health Services Block Grant, Epidemiology and Laboratory Capacity–Emerging Infectious Diseases (ELC-EIP), HAN, NEDSS and electronic health data and informatics (EHDI). NEDSS system developers should "leverage" the base, since the initial development is the most difficult part. Once the Base System is in place adding programs and modules are accomplished more easily.

Discussion Points

Following the presentations there was a discussion period among all session attendees.

- ***Getting buy-in from important public health entities and other organizations –*** The panel members and moderators were asked for advice on how to convince organizations to participate in funding and implementing NEDSS. Key steps are:

  a. Finding out what others need and showing them how NEDSS can meet those needs.
  b. Finding early adopters who can help enlist others later.
  c. Focusing on newer organizations and organizations with DOS-based or totally paper-based systems since they may have the greatest needs.
  d. Looking for organizations with a relatively solid funding base. Point out that NEDSS may cause short-term disruption, but will make addition of future program applications easier.

- ***Frist-Kennedy funding –*** Interest was expressed in receiving funds through Frist-Kennedy legislation to assist in implementing NEDSS. Dr. Baker indicated that the legislation authorizes grants to build state and local public health infrastructure, including communications systems. No appropriations have been made to implement the legislation, but may be included in future Federal budgets.
- ***Advice on software development –*** Both panelists advised participants to purchase open market software from companies that can provide technical support. It is important to standardize the types of development tools early in the process. Colorado found Microsoft to be a good fit but considered using some free open source tools (Linux platform, etc.). Massachusetts engaged Science Applications International Corporation (SAIC) in a vendor relationship to help develop software. Providers like SAIC bring a wealth of knowledge and resources and can work on a fixed-cost basis.
- ***Exchange of data with local health departments –*** Local health structures differ in Colorado and Massachusetts. Currently, some local health departments must enter data in a resident database system and duplicate the data entry process for the state-wide system. Both states' systems are web-

based so that local health departments and others have ready access. This is an ideal solution because Internet-based systems require minimal hardware and software for the local health departments. The type of data that can currently be entered by local participants varies, but the long-range goal is to permit them to enter raw data as well as report summaries.

- ***CDC support*** – Dr. Baker asked panel leaders to identify the single most important things CDC could do to help implement NEDSS. Support was expressed for the current CDC approach of focusing on developing standards and providing funding. CDC needs to provide final standards as soon as possible, since this will help State and local implementers and will encourage private development of software. The provision of training through HAN also needs to receive higher priority.

Meeting Outcomes

- CDC is committed to building base-infrastructure for public health across the United States. This infrastructure is focused around information technology, public health workforce, and organizational capacity. CDC is accomplishing this through HAN, NEDSS, and the Frist-Kennedy Bill of 2000.
- The U.S. Congress is also committed to building public health infrastructure by providing funds through HAN, NEDSS and the Frist-Kennedy Bill of 2000.
- The state of Massachusetts is in the process of developing a HAN portal that is user-friendly and will be used on a daily basis. Massachusetts approached the issue of building the infrastructure by partnering with tobacco control who had IT needs and money to spend.
- The state of Colorado is developing an electronic surveillance system focusing on long-term needs. In choosing tools utilized by the system, Colorado did not base their decision on technology, but rather on existing staff that could support those tools. One obstacle that Colorado faced was locating money to build the infrastructure. Colorado received money from HAN and NEDSS, but also found additional funds from programs that adopted the surveillance system in the early stages of development.

C. Panel C: Opportunities for Public Health through Vital Statistics and NEDSS

Moderators: Alvin Onaka, Hawaii State Department of Health, National Association of Public Health Statistics and Information Systems
Mary Lou Lindegren, National Center for HIV, STD and TB Prevention, CDC

This session focused on the role and implementation of electronic birth and death records for NEDSS and surveillance. The panelist for this session were Delton Atkinson from the National Association for Public Health Statistics (NAPHSIS), Garland Land from the Missouri Department of Health, Pamela Akison also from NAPHSIS, and Mary Ann Freedman from the National Center for Health Statistics.

Delton Atkinson – NEDSS and Vital Statistics

Mr. Atkinson began by asking whether a NEDSS-vital statistics partnership is a new frontier. Vital statistics is the oldest system in public health statistics, and is both an administrative system and surveillance system. As a system for gathering surveillance data, vital statistics provides data on births and deaths, and should provide data that are of high quality, cause minimal burden and are easily accessible. As an administrative system, vital records have multiple legal functions; concerns include: lost or stolen certificates, fraudulent use, amendment, issuance and customer satisfaction.

There is a need to link the administrative and surveillance aspects of vital records to NEDSS and NEDSS uses. Reengineering or "e-vitals" is one way to link these two systems. Such a reengineering would recognize the perceived limitations of vital records, such as, inadequate access, legal restrictions, inadequate customer service, reliance on paper records, the lack of state of the art technology, and surveillance limitations including timeliness, quality, and burden on the provider. Reengineering should provide rapid issuance and reporting across transaction types (Government to Client, Government to Government, Government to Business, Client to Business), and instant feedback to providers of data.

The difficulty lies in how to accomplish these goals without wasting time, while simultaneously preventing fraud, maintaining strong security procedures, improving customer service, and automating population of other systems. A reengineered administrative system will provide a sound surveillance system by design alone. Getting to this reengineered system will require partnering, process and data standards and a focus on electronic systems. The next steps in moving toward that reengineered system are:

- an improved understanding of vital statistics
- pilot implementations of E-systems with standards and electronic interchange
- consensus on data standards for web dissemination, and
- partnerships in an e-vital statistics world that will bring together essential communities.

Garland Land – Opportunities for Public Health through Births and NEDSS

Dr. Land spoke about the current strengths of birth records in most states. In Missouri, birth certificate data already have enhanced data sharing around infant deaths; immunization registries; birth defects;

newborn screening and newborn hearing; women, children and infants; Medicaid; hospital discharges; special health care needs; lead; and STDs. Birth records are fundamental building blocks for other programs sponsored by CDC, United States Department of Agriculture (USDA), Health Resources and Services Administration (HRSA), and the Social Security Administration. Therefore, birth records could be the hub for an integrated data repository and need to be considered within the NEDSS system. Federal agencies should collaborate to support integrated birth information systems, not just reportable diseases, in a single system.

Pamela Akison – Death Records: The Ultimate Outcome of the Dataset

Dr. Akison discussed the differences between death and birth records. Unlike birth records, death records are rarely reported in an electronic form. Death records, like birth records and all vital records, serve as both legal records and surveillance data. Moreover, death records are not a target for archiving because they must be kept forever, making the need even greater for electronic formatting. Death records can serve as key public health statistics and provide cause of death data that will perhaps lead to recognition of unrecognized diseases. Death records need to be linked to other registries for outcome analyses. Unusual partners are needed to reengineer death records because funeral directors enter demographic information, while physicians and coroners enter the cause of death. Speed is of the essence with death records as they must be completed within 3 days of death and prior to burial.

The Social Security Administration is piloting the Electronic Death Registration System (EDRS). This pilot system will verify social security numbers online and report deaths within 24 hours. It is being built on current and evolving standards including the Public Health Conceptual Data Model (PHCDM) and the Health Insurance Portability and Accountability Act (HIPAA) requirements for security, privacy and digital authentication. EDRS is being designed to be compatible with NEDSS in recognition of the importance of integration.

Mary Anne Freedman – Vital Statistics the National Perspective

Dr. Freedman addressed the statistical uses of vital statistics rather than the legal components. There is no Federal law controlling vital statistics; rather, the system is decentralized and based in state and local law. Discussion about vital statistics can be broken down into timeliness, standards, strengths and weaknesses, and future direction. The timeliness of vital statistics is critical and depends on data flow, interventions at each step of collection, transmissibility, and level of responsiveness at a state and national level. Standards – such as standard vital certificates, model laws, and data specifications – are necessary if the timeliness of data are to be improved. There are a number of strengths and weaknesses associated with the current collection of vital records as surveillance data. Decentralization, "weakest link" issues, and resistance to change are problematic. On the plus side, however, there is a great opportunity for cooperative partnerships, the data have great analytic strength, and there is a long history of vital statistics collection. Future goals must include the

reengineering of the birth and death systems through process change, the implementation of new standards, and improvement on work completed so far.

Meeting Outcomes

- Currently, the vital statistics system is not technologically advanced. Death, fetal death and induced abortion registration systems are paper-based. Although birth registration is an electronic system, it is based on 1970s technology and varies from state to state.
- There are several common goals between NEDSS and a re-engineered vital statistics system: create data standards, reduce data development efforts, enhance data sharing, representing public health data needs to national standards setting bodies and facilitate collaboration between CDC and its state and local partners.
- A major theme in this panel discussion was the integration of vital statistics into NEDSS in order to communicate with other information systems to enhance data sharing. The panelists characterized the vital statistics system as serving two functions: one, a public health surveillance systems including notifiable diseases, maternal and child health data needs and chronic disease registries; and two, an administrative data source for federal agencies such as the Social Security Administration and for child support enforcement.
- Using birth certificates as a hub for information, an integrated data repository could be a data source for the statistics on women, infants, and children; lead testing; new born screening; new born hearing; birth defects; immunizations; and SHCN.
- Immediate next steps identified by the panel are to include an article about this NEDSS conference in the NAPHSIS April newsletter and brief the attendees of the NAPHSIS/NCHS Annual Meeting in May on NEDSS and common goals with vital statistics.
- Long-term next steps are to convene a CDC/NAPHSIS planning meeting in order to develop an action plan, identify strategies to include other federal partners, develop a NEDSS process model, identify pilot projects and share outputs with states.

D. Panel D: Policy Issues Around NEDSS: Data Sharing, Access and Confidentiality

Moderators: Gianfranco Pezzino, Kansas Department of Health and Environment Dan Jernigan, National Center for Infectious Diseases, CDC

It is hoped that the implementation of NEDSS will increase the efficiency and rapidity of public health access to needed data. This session discussed some of the policies and options available for sharing data and protecting its confidentiality, and described how these issues have been addressed in some state public health agencies. Dan Jernigan from the National Center for Infectious Diseases, Jac Davies from the Washington State Department of Health and Perry Smith from the New York State Department of Health addressed policy issues, technical solutions and the direct implementation of NEDSS.

Dan Jernigan – Policy Issues Around NEDSS: Electronic Lab-Based Reporting (ELR)

States have varying requirements for reporting findings for public health importance. Additionally, there are separate requirements for clinical providers and laboratory providers . Electronic Laboratory-Based Reporting (ELR) will improve the timeliness and completeness of disease reporting. Both NEDSS and the Base System have an ELR function in its design. ELR helps reporting move towards a more integrated environment and automates the capture and transmittal of information. State and Federal laws have varying requirements for how information is handled, who has access, and what method is used for reporting. For the NEDSS system, standards will need to be developed for consistency among all states. There are clear benefits in moving lab-reporting systems from paper to electronic format. After the initial setup, an ELR uses fewer personnel, saves time with efficiency, and make content easier to transmit. With encryption and audit trails, electronic formats are ultimately more secure than paper.

There are also several requirements for ELR in NEDSS Base System, functionally and technically. Information must comply with the state standards regarding routing and security. Several layers of encryption may be needed to allow only the parts of the record intended for a recipient to be reviewed. The system ensures secure transferal over the Internet by using secure pipelines between the state and CDC. Communication between national labs and states will be routed through a hub, but not read to ensure privacy. The technical standards considered at this point are SilverStream application servers, E-link translators, Health Level 7 (HL7)-compliant eXtensible Markup Language (XML) as a messaging format or Systemized Nonmenclature of Medicine (SNOMED) as data types.

Jac Davies – Data Sharing Issues in the Age of NEDSS

Ms. Davies discussed data sharing issues and how various policies affect NEDSS. Nearly every state has different policies on data sharing based on the type of data involved. For example policies for HIV data are typically more stringent than for vital statistics. At present, it is acceptable to have differing data sharing policies among states.

The Public Health Issue Management System (PHIMS) in Washington State is similar to NEDSS. The PHIMS acts as an active server page (ASP) for local health departments with the database and application in a central location. Rules and policies ensure proper security and access to various levels of data. For example. some HIV data policies prohibit full integration. Trust must also be established so that local health agencies have confidence their data will be protected.

People and technology must be used to help maintain the rules. Technology can be designed to control data access, but people must enforce those policies to make sure the controls work. For example, when staff change jobs or roles, their access rights also need to be adjusted. It is important to maintain control and to respect who has control. This will promote "buy in" of users and enable a successful system.

In the State of Washington, the Epidemiologic Query and Mapping System (EpiQMS) is a browser-based analysis and geographical information system (GIS)-mapping tool. The current prototype contains death, cancer, hospital discharge and sexually transmitted diseases (STD) data. Users of EpiQMS are assigned an access level when they sign up to use the system. Data stewards determine the appropriate level of access according to the data the user wants, are responsible for controlling that access of users over time.

The future holds both policy challenges and opportunities. The primary challenge is to support technology while keeping in mind that public health needs and rules do not change. New technology affords the opportunity to share data more efficiently, but data sharing agreements should change as technology advances.

Discussion Points

Following Ms. Davies' presentation, there were a few questions from the audience.

- ***Vital Statistics Data –*** *In incorporating vital statistics, will the data be collected historically?* The vital statistics data are aggregated. As long as the dataset has common attributes, incorporating vital statistics historically can be accomplished. However, there needs to be a reality check to make sure that all data are available.
- ***Registry Matching –*** *In performing registry matching with ELR, how are matching and subsets handled?* This problem is still being resolved.

Perry Smith – Data Sharing, Access and Confidentiality – The New York Experience

Dr. Perry Smith discussed confidentiality, gave a brief overview of the New York system, and described what is involved in making policy decisions as it relates to technology. In New York, local health departments communicating with clinical labs and providers via secure encrypted links over the Internet. This system requires only an Internet connection and web-browser so is accessible from virtually anywhere. The key to maintaining security is using differential rights and access. There are several layers of access including physical security, firewalls, proxy servers, and application filters to ensure data integrity and proper access. To ensure ease of use, the system utilizes single-sign-on to access data, applications, and web services.

When identifying policy rules, feedback is solicited from Information Systems, Legal, Executive leadership, Local Health Units (LHUs) and the Programs. Policy rules typically stem from the needs of the programs, since the programs house the experts and determine constraints on data access.

Several barriers to implementation were identified:

- "One size does not fit all" when developing systems.
- Multiple passwords must be used and security measures established.
- The system must accommodate changing data needs
- It is difficult to find enough resources to complete the project and supply ample training.

Lessons learned were to involve system users early in the planning stage and keep them updated. Also, the system should be constructed modularly, starting small and allowing time to grow.

Discussion Points

Following the presentations there was a question and answer period.

- ***Role of Local Health Departments –*** *Local health departments are the agencies that really use the information in the surveillance systems; however, most policy language concerns CDC or the state level. How can this issue be resolved?* There is a need to pay more attention to the local level and to cater to their policy needs. Language must be included in policies that will accommodate local health departments.
- ***Decentralized Security Model vs. Centralized –*** *What model is best?* The state of New York has de-centralized security since the state level lacks the resources to do otherwise. Therefore, the program office is responsible for granting access, though there are also checks on this system to ensure that access is being granted correctly.
- ***Soft Policy Issues –*** *How are situations handled in which data are misinterpreted?* The technology has not changed access to data; thus, the old problems still remain. One solution is to educate and train personnel in how to interpret data correctly. A related issue is trying to decide what information to put on the website.
- ***Resources –*** *How many people does it take to develop and maintain these systems?* The main development of the system involved only one or two programmers over a long period of time; however, there are several funding streams for programmers, trainers, etc. to use.
- ***Tribal Communities –*** *How will tribal communities fit into this system?* Like the military, the health facilities will be involved.
- ***Value –*** *How can the value of this system be judged, especially with all the money that is being funneled into this project?* New York was able to develop a

full surveillance system for a specific disease agent (i.e., West Nile Virus) in only a few months. There is value in that.

Meeting Outcomes

This panel discussed issues related data access, confidentiality, data sharing, and data display in electronic information. There were a number of common themes discussed by all the panelists.

- There is a strong need to involve current surveillance staff who work with the programs that are and will be affected by NEDSS in the planning and implementation phase. It might also be appropriate to give the programs complete control over who has access to electronic data, as they do now with a paper-based system.
- Issues concerning data access, confidentiality, and security have not changed because surveillance information is now electronic rather than paper-based. Our roles, laws, and regulations have not changed, rather specific issues have become real and new challenges emerge.
- Concerning the legality of electronic data reporting, the main point discussed was, to what extent can state agencies host information that does not belong to them. In one case, legal opinion ruled against the public health entity storing information that belongs to local heatlh departments, labs, providers, etc.
- Another common theme discussed was data warehousing and accessing this data electronically. Technology makes it possible to visualize and display a higher level of detail than was possible with a paper-based system. However, it is important to ensure confidentiality of local information. It is possible for the users of the system to view and display small cell data.

Due to time constraints, the panel was unable to address solution to these issues.

E. Panel E - NEDSS Relationship with Other Programs

Moderators: Larry Hanrahan, Wisconsin Division of Public Health, Council of State and Territorial Epidemiologists
Steve Thacker, National Center for Injury Prevention and Control, CDC

This session focused on relationships and implications of NEDSS to partner public health programs, including infectious disease as well as injury and environmental health surveillance. Linda Mattocks from the Ohio Department of Health, Xen Santas from the National Center for HIV, STD and TB Prevention, Susan Cummins from the National Center for Environmental Health, and Dan Pollock from the National Center for Injury Prevention and Control discussed their experiences with NEDSS partners.

Linda Mattocks – NEDSS Relationship with Other Programs

Ms. Mattocks discussed the Ohio Disease Reporting System (ODRS) and the relationship with NEDSS. The ODRS is a web-based database in a central location that is managed by the Ohio Department of Health, but it is also accessible by local health departments. Some important considerations that Ms. Mattocks highlighted were that person and event matching is critical, so that a case is counted only once; reports will go through a series of data cleaning for quality assurance; and some security and confidentiality concerns exist. The operations plan calls for the ODRS to act as a centralized intake for case reports. The reports will then be exported to STD*MIS for case determination, case investigation and partner notification activities. Morbidity reports will then be sent back to ODRS from STD*MIS. In the future ODRS will increase the functionality of data and case reporting; as NEDSS modules are developed, they will be added to ODRS for easier case management.

Discussion Points:
Following Ms. Mattocks' presentation, there were a few questions from the audience.

- ***Relationship with Local Health Departments –*** *Are agencies on the local level satisfied with the system and how is their support maintained?* Ohio staff continually meet with local partners to make sure that ODRS is meeting their needs. Extensive communication is needed to keep all partners satisfied.
- ***Linkage of two Databases –*** *As it was presented, there are actually two databases in ODRS. Will these ever become one database?* Ohio is working towards integrating the two databases into one database. However, two issues are involved: security and case management. Both of these needs must be met in a single database for all partners to be satisfied. There is hope that the NEDSS modules, especially concerning HIV/STD, can help integrate the two databases.

Xen Santas – NEDSS Relationship with HIV/AIDS Program

Mr. Santas discussed the relationship between NEDSS and the HIV/AIDS Reporting System (HARS). HARS is a large system that allows local variation; data standardization is built into the system. However, the system is also old and based on outdated technology that is hindering effective HIV/AIDS surveillance. The Statistics and Data Management Branch (SDMB) determined ways to improve HARS. SDMB has also been conducting regional meetings with state representatives to ask what they would like in a new surveillance database. This list has become fairly extensive, but the top request has been the ability to track case finding activities. SDMB has also develop a number of prototypes of the redesigned database that are being tested. Redesigning HARS is part of the NEDSS development process and HIV/AIDS staff have worked on each aspect of NEDSS. There have been very few barriers to this development process. The next step is the implementation phase which includes staff training, system design, development of guidelines on security and data, access, and prototype development.

There was one question from the audience following Mr. Santas presentation

- *Will HARS be stand-alone or IDR?* HARS will be compliant with NEDSS standards. It will be implemented to be compatible with IDR, but it is not required yet. States will be able to choose whether or not to use IDR. In designing HARS, everything has been designed to be IDR compatible.

Susan Cummins – Pew, NEDSS & Environmental & Chronic Disease Surveillance

The Pew Environmental Health Commission convened from March 1999 to December 2000. They were appointed to study the nation's capacity to track chronic diseases and assess links to environmental factors. A few of the problems identified by Pew were the limited tracking of chronic diseases, the lack of standards and the difficulty of linking chronic diseases to environmental factors. The Pew Commission made a few recommendations including a national baseline tracking network for disease and exposures and the capacity to link tracking efforts to communities and research. CDC must now provide Congress with a plan that responds to Pew's findings. The agency has convened workgroups to develop a framework and response plan. CDC's response will require a seamless, efficient, cross-cutting approach to chronic disease surveillance and environmental hazard surveillance. NEDSS is one mechanism that will help CDC and state partners to accomplish this task.

Dan Pollock – NEDSS Relationship with Injury Prevention and Control

CDC has been involved in the development and use of Data Elements for Emergency Department Systems (DEEDS). The funding for this program came from NEDSS. DEEDS is currently being used by the Emergency Department of the Oregon Health Sciences University and the Oregon Health Division (OHD). When a patient arrives in the Emergency Department, information concerning the injury (cause, circumstance, severity, etc.) is entered into DEEDS creating an electronic medical record. Once a day the reportable data elements are sent in HL7 format to the OHD through a secure transmission. These elements can now be accessed by public health data users at the OHD. DEEDS and NEDSS are key steps in connecting public health to clinical information systems. Significant accomplishments by this project are: 1) the transfer of data from a clinical setting to the OHD, 2) the development of data security using encryption and designated users, and 3) the increase in reportable conditions. Through a study it was discovered that 90 % of pelvic inflammatory disease (PID) cases were reported through DEEDS, and not through laboratory reporting channels. Next steps for this program include adding more reportable conditions, adding another emergency department and enhancing the capacity for sexually transmitted diseases

(STD) follow-up. Adherence to NEDSS architecture and guiding principles will yield important benefits for surveillance.

Meeting Outcomes

There are several surveillance programs that are well underway in the planning and implementation processes of NEDSS development. Some examples of these programs were presented in this panel and all are at various stages of development.

- The Ohio Health Department is well underway to having a web-based and NEDSS-compliant STD reporting system.
- HARS is currently upgrading its system to be NEDSS-compliant and hopes to have a beta system out later this year. HARS has placed a lot of emphasis on guaranteeing privacy and security in the new web-based database. HARS is also addressing stakeholders' issues through the development of modules.
- The Pew Charitable Commission conducted an assessment of public support focused on chronic diseases and environmental exposures. This would include tracking environmental hazards, exposures and health outcomes. This level of surveillance would require a cross-cutting systems that would be composed of more than one database. The NEDSS architectural standards will provide the implementation framework necessary for CDC to respond to the commission's findings.
- DEEDS and emergency room surveillance is basically implementing HL7-RIM standards. This is a prime example on how a program is connecting NEDSS to HIPAA standards concerning electronic medical records.. Through this program, public health surveillance using NEDSS is being utilized in a clinical setting.
- Closing Observations
    a. There are programs developing electronic surveillance systems that will adhere to NEDSS standards.
    b. The key challenge is to maintain communication on these efforts
    c. Involve stakeholders through meetings and conferences
    d. Reach out to new partners, including environmental agencies
    e. Communicate solutions, post to WebBoard.

F. Panel F – Implications of the Health Insurance Portability and Accountability Act (HIPAA) for NEDSS

Moderators: Richard Hopkins, Florida Department of Health
Gib Parrish, Epidemiology Program Office, CDC

NEDSS standards are not restricted to use for surveillance of infectious diseases. The Health Insurance Portability and Accountability Act (HIPAA) provides an opportunity to extend surveillance and to link public health and clinical medicine more closely . This session focused on the administrative simplification provisions of HIPAA and the implications for NEDSS, including issues related to public health representation at relevant standards development organizations (SDOs). Majorie Greenberg from the National Center for Health Statistics, Pamela Akison from the National Association for Public Health Statistics and Information Systems (NAPHSIS), Denise Love from the National Association of Health Data Organizations (NAHDO), and Jason Goldwater from the Health Care Financing Administration (HCFA) discussed the opportunities that HIPAA provides for NEDSS.

Majorie Greenberg – Standardization of Health Data – With Public Health at the Table

Ms. Greenberg provided an overview of HIPAA describing it as providing a national framework for: electronic data interchange, health data standards, and health information privacy, directed towards improving efficiency and effectiveness of the health care system. Activities over the last few years in developing the specifics for HIPAA have served to stimulate collaborative work on health data standards, particularly among public health, Medicaid, and Standards Development Organizations (SDOs). The design of HIPAA related health data standards provides an opportunity for improving access to clinical data by public health information systems due to the specific standards required by HIPAA and the processes and time lines for codifying them. The Public Health Data Standards Consortium (PHDSC) has also done extensive work in this area and played an important role in convening organizations around data standards issues and identifying high priority data needs. PHDSC interests include HIPAA claims- related data, birth and death data, disease registry and surveillance data, and birth defects data. Some of the early lessons learned
includes the need for education on HIPAA and data standards within the public health community, the recognition that partnerships between Federal and state levels are important, and the realization that there is strength in numbers.

Pamela Akison – HIPAA, SDOs and Public Health

HIPAA has awakened everyone's interest in health data standards and has set the stage for understanding and adoption of such standards. Ms.Akison described the process for establishing a health standard:

- Identify the needs – build a strong business case for the benefits to be gained
- Garner support among users – identify the business partners
- Identify the ideal solution – develop a strong business proposal
- Identify a venue – design a system appropriate to participants
- Create a request for maintenance
- Present request at SDO – present business process requirements
- Network for support

The electronic death record can illustrate the process of developing a standard. NAPHSIS has also played an important role in health data standards development as

collaborators and as advocates of the interests of their primary constituents, the state centers of health statistics and vital records. There is an important need for a mechanism to rationalize and coordinate the activities from different sources, e.g., PHDSC, NEDSS, individual agencies, and SDOs themselves.

Denise Love – Implications of HIPAA for NEDSS

There are three major benefits of HIPAA: 1) enabling technologies and policies for true data exchange; 2) formalizing cultural change for data development and exchange; and 3) providing opportunities for public health to define its business partners and transactions. Hospital discharge data have an increasing role in the health information infrastructure, especially with the emerging systems to capture non-inpatient data. Discharge data systems are important for NEDSS as a source of surveillance data, a link to other major data sets, and an opportunity to apply analytic methods to identify patterns and proximity measures. The timing is right to improve our health data systems. There are numerous forces converging to set the stage for needed changes: HIPAA, NEDSS. UB92 (uniform billing 92), PHDSC, Internet, and National Quality Report and Patient Safety. One of the challenges is that HIPAA was designed in a health care industry context, not for public health. Public health must be aggressive in getting its voice heard, since data not collected for payment may not be collected at all. NAHDO has been involved in developing HIPAA strategies by providing HIPAA education at each meeting and teleconference, actively participating in the PHDSC, joining relevant work groups, and assisting in the development of the Health Data Standards Implementation Guide.

Jason Goldwater – Administrative Simplification: Medicare and Public Health

HIPAA represents an opportunity for creating a stronger partnership between public health and Medicaid. There are a number of potential positive effects of standardized data on Medicaid programsthat may have emerged through HIPAA, such as increased quality of care, better case management, overall reduction in Medicaid expenditures, and increased monitoring for access issues. However, there are some potential negative effects, such as cost and effort for implementation, short time frame for implementing standards after they are final, increases in Medicaid operational costs, and changes in policies and reimbursement. Potential benefits of HIPAA to public health include: better analysis of populations, leading to better case management, leading to better prevention methodologies. A unified linked system containing clinical information including diagnosis, procedures, test results, and other factors would be an asset to determine disease etiology, and more comprehensive epi-profiling. Currently public health data elements are limited in the proposed data standards; public health strategies to include more elements must meet the realities of the health care business world. For years Medicaid and public health have been viewed as two separate entities, with Medicaid an insurance program and the data in the Medicaid Management Information System (MMIS) useful only to adjudicate claims. The partnership that occurred in many states around immunization registries provides an example of how public health issues can be integrated into Medicaid. There is the potential for examining other ways of using new technology to assist in the retrieval of public health information from the MMIS.

Discussion Points

The question “How do we connect the dots?” was asked. Each panelist responded and the following points were made:

- Medicaid has three major issues; quality of care, access, and effective case management. These issues align closely with those of public health.

- Public health managers need to talk to each other to consolidate and strengthen efforts for presenting the case for public health standards.
- Public health and the health care communities have mutual interests in strengthening the health data infrastructure.
- If public health does not buy into HIPAA, providers will direct them to do so and will refuse to accept duplication.
- Public health must explore the use of administrative as well as clinical health care data.
- Eventually the use of a common electronic medical record will bring all parties together.

Wrap-Up

Dr. Richard Hopkins closed this session by noting the lack of a single reference to communicable disease. HIPAA is forcing people from different domains to work together to improve the health information infrastructure. Public health practitioners must learn to make strong business cases in proposing standards. State epidemiologists should work more closely with state counterparts in Medicaid, health statistics, and hospital discharge registries to implement HIPAA data standards. There is also the need to keep the departments of public health focused on HIPAA opportunities, not just acute problems such as privacy provisions.

Meeting Outcomes

There were several common elements in all the presentations in this panel.

- HIPAA is making people from different areas (public health, Medicaid, hospital discharge, payer, provider communities) are having to talk to each other and find solutions to common issues. Additionally, public heatlh people from different parts of agencies are having to communicate on issues concerning HIPAA and NEDSS.
- One of the challenges of HIPAA is that public health people need to learn to make business cases for collection of data elements that are importnat from a public health point-of-view in ways that are convincing to those in the private sector who have to pay for the collection of data.

- During this entire discussion, there was no discussions around communicable disease, rather the discussion focused on data systems and data elements. The same issues are present regardless of the program (infectious disease, injury, etc.)
- Complying with HIPAA provides a system for health care providers to pass data to public health entities. There is a need to focus on both the administrative and clinical content of standardized records.
- Facts on HIPAA

    a. The final rule of transactions and codes sets was published in August 2000 and becomes effective October 2002.
    b. PHDSC has taked the lead on modifying the content of data records. In particular, a change to add fields for race/ethnicity and mother's medical record number to link a child's and mother's medical records.
    c. There is also a plan to develop a Health Care Service Data Reporting Implementation Guide.

- Some state's immunization registries are integrating their activities with the Medicaid Management Information System. This is requiring public health programs and Medicaid programs to work together in a new arcana.
- Forty-four states have hospital discharge systems, not al of which are in the public sector. A large majority of these are not accessible to public health entities. Twenty-five states have ambulatory surgery systems and fifteen have emergency department systems. All of these could potentially feed into NEDSS.
- Next Steps

    a. Need to identify who will coordinate various data efforts.
    b. Need to coordinate educational activities between NEDSS effort and PHDSC.

VII. CLOSING REMARKS

Jerry Gibson, South Carolina Department of Health and Environmental Control, Council of State and Territorial Epidemiologists
Steve Hinrichs, Nebraska Public Health Laboratory, Association of Public Health Laboratories
Claire Broome, Senior Advisor for Integrated Health Information Systems, CDC

Jerry Gibson had two closing thoughts to share with the audience. One, always plan for activities to take longer than originally thought. Two, there is a need for more marketplaces or clearinghouses to share the different solutions that states are developing, e.g., scopes of work for contract, draft policy framework, software solutions, etc. The WebBoard performs this function, but we other marketplaces should be investigated.

Providing a laboratorians point-of-view, Steve Hinrichs closing message was that states should include a lab component in their grant applications. States should also include a laboratorian in the planning committees and activities to account for this viewpoint.

In her closing message t, Dr. Broome emphasized that Federal funding is critical to launching NEDSS, but will be insufficient for full implementation. Unfortunately there will be more applications for NEDSS funding than there is money to support the grantees. The implication of this is that all states need to find additional funding from various sources. It is also important to find a way to document the benefits of NEDSS and its success in order to justify needed funding. One suggestion for measuring the success of NEDSS is to identify the differences that NEDSS makes in public health, such as early detection of food-borne illness occurring across state lines and quicker surveillance, resulting in more rapid and better-informed intervention in outbreaks. Another means to measure the success of NEDSS is to look at the costs of not implementing NEDSS. This includes the costs of managing multiple, separate systems; costs of modifying current obsolete systems compared to modifying a modular system; and time diverted from investigating outbreaks and carrying out public health programs in order to manage inefficient data systems.

Dr. Broome thanked those who had organized and participated in the meeting. She particularly acknowledged those in the audience who had embraced the opportunity that NEDSS presents to improve their daily public health work, and who had contributed to the arduous efforts of the past two days by sharing their experiences, challenges and opportunities.